ENHANCING ACCESS TO CARE FOR SICKLE CELL DISEASE IN SOUTH CAROLINA

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Outline to Enhance Access to Care:

- Evaluate the Disease Process
- How to Evaluate a State
- What is happening in your state NOW (South Carolina)?
- Framework to develop a comprehensive state (SC) sickle cell disease plan
- Using what we have available
- Setting up combined goals
- Planning for Sustainability

Evaluate the Disease:

- Sickle Cell Disease (SCD) is the most common inherited blood disorder in the United States
- Affects approximately 100,000 individuals
- More than 98% of affected persons in the US are African-American, African or Black American
- **Highest cause of 30-day readmission in most hospitals in South Carolina**

Why is Sickle Cell Disease hard?

- Patients are living longer with SCD
- Adults are highly underserved and often live in rural areas where they do not have access to specialized care
- There are not enough physicians trained to care for persons with SCD
- The majority of primary care and emergency department physicians have not received education in SCD management.
- PCPs are often unwilling or uncomfortable with SCD patients
- **As a result of these systemic issues, adults with SCD are often forced to rely on urgent care treatment, which is not disease or patient-focused.**

What could improve the care for individuals with Sickle Cell Disease?

- Identification of a medical home that can provide “wrap around” care that follows national guidelines
  - *Access to a disease specialist*
  - *Access to individualized treatment*
  - *Access to a social worker*
  - *Better medicine, closer to home*
  - *Someone that can hear the patient’s needs*

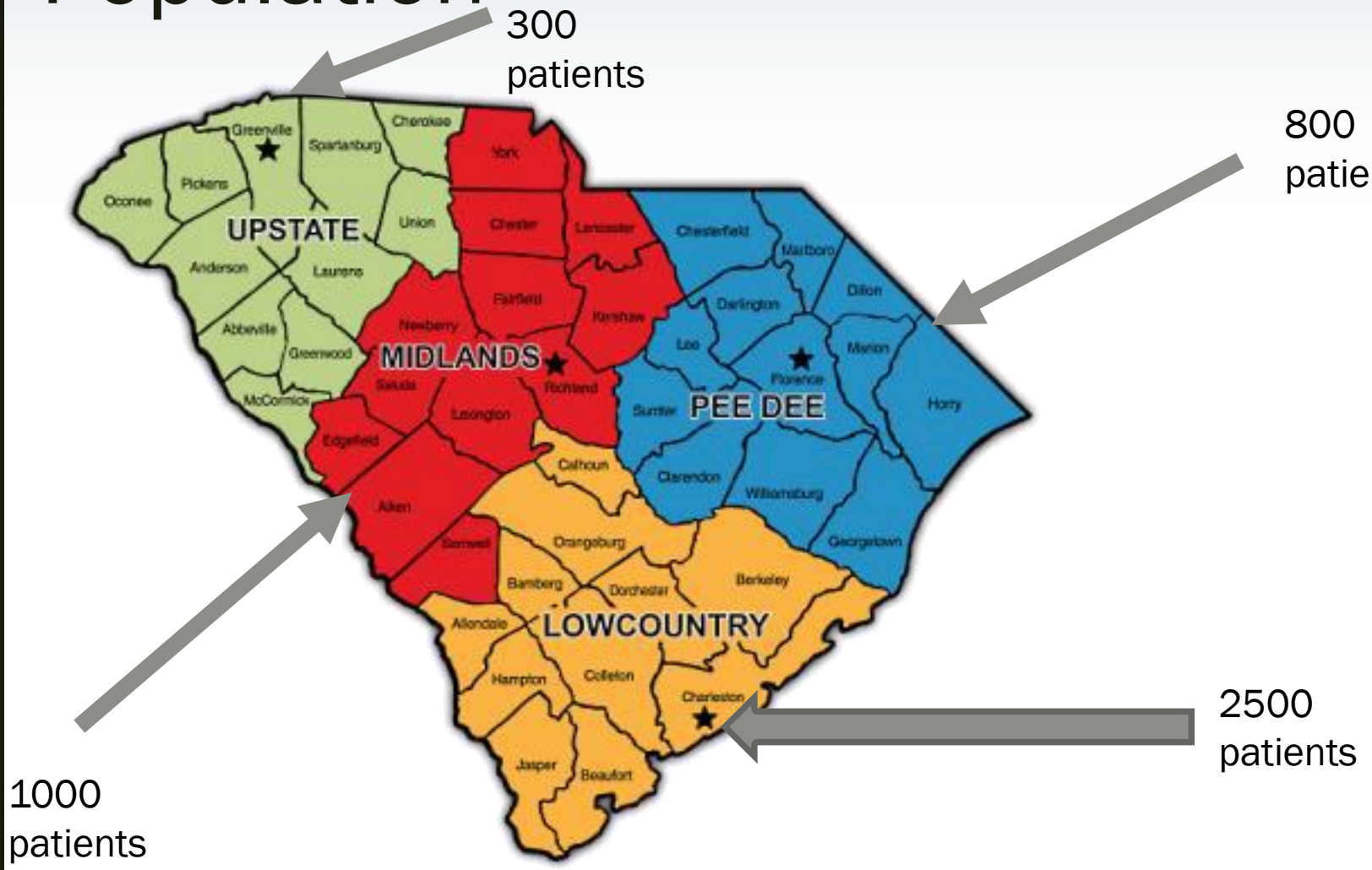
Evaluate your state:

- How many individuals with this disease need treatment
- Who are the statewide stakeholders
- What are the barriers (internal and external)
- Who are the facilitators
- Identifying allies (& enemies)

What is happening in South Carolina?

- Sickle Cell Disease is highly prevalent in SC
  - *Data estimate up to 4500 persons with SCD*
- SCD is a “hospital problem”
- Most hematology groups are unwilling/able to take patients >18
- Lack of quality improvement in SCD
- Lack of statewide protocols
- Pharmacy/Prescription ordering is poorly coordinated and often works against the patient to improve care
- Care coordinators/Case Managers are not coordinated and likely underutilized

Overview of Sickle Cell Disease Population

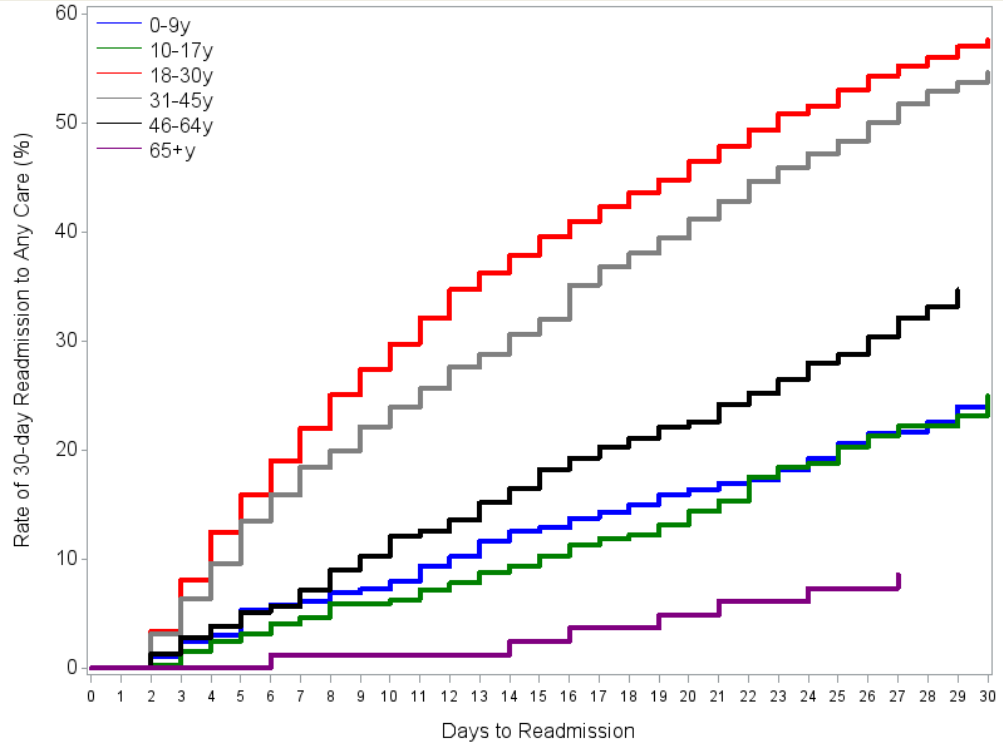


Where are SCD patients receiving acute care?

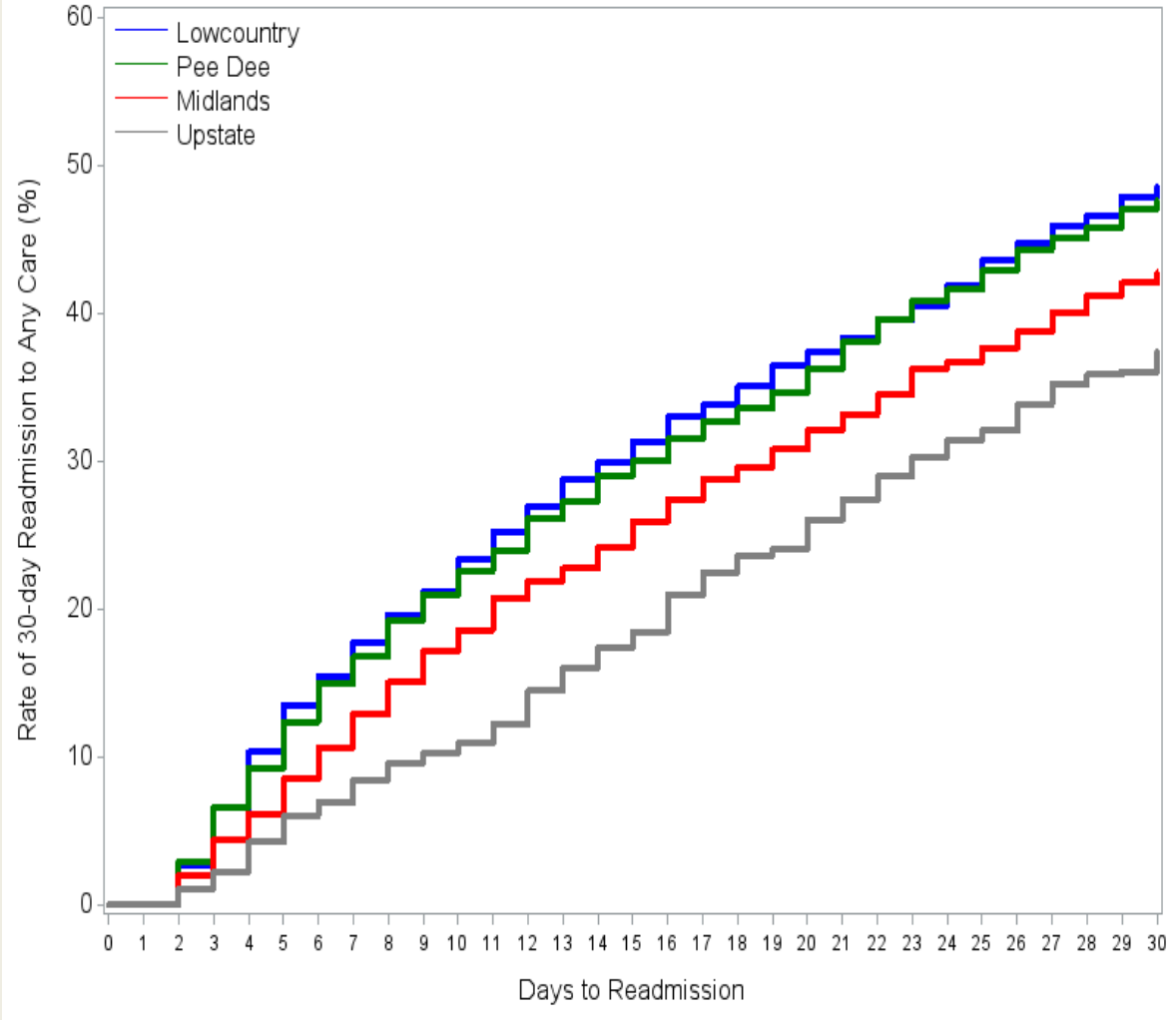
	Patients, No.	Encounters per Patient, No. (95% CI)		
		ED	IP	Total
Total	2313	2.90 (2.63-3.17)	1.74 (1.62-1.85)	4.64 (4.30-4.97)
Age, y				
0-9	473	1.08 (0.97-1.18)	1.33 (1.17-1.49)	2.41 (2.22-2.59)
10-17	272	1.31 (1.12-1.50)	1.28 (1.08-1.49)	2.59 (2.28-2.90)
18-30	713	4.92 (4.24-5.60)	2.25 (1.99-2.50)	7.17 (6.34-7.99)
31-45	478	3.77 (3.05-4.84)	1.94 (1.65-2.23)	5.71 (4.82-6.60)
46-64	290	1.75 (1.33-2.17)	1.46 (1.20-1.72)	3.21 (2.64-3.78)
≥65	87	0.30 (0.19-0.41)	1.03 (0.84-1.23)	1.33 (1.17-1.50)
Region				
Lowcountry	808	3.83 (3.23-4.44)	1.82 (1.62-2.01)	5.64 (4.94-6.35)
Midlands	613	2.44 (2.08-2.80)	1.48 (1.29-1.68)	3.92 (3.44-4.40)
Pee Dee	541	2.74 (2.20-3.28)	2.14 (1.87-2.41)	4.89 (4.17-5.60)
Upstate	351	1.80 (1.39-2.21)	1.38 (1.15-1.61)	3.18 (2.66-3.71)
Expected payer				
Medicaid	1057	2.84 (2.46-3.22)	1.95 (1.78-2.13)	4.79 (4.31-5.27)
Medicare	559	4.57 (3.77-5.36)	2.46 (2.18-2.74)	7.03 (6.09-7.96)
Private	486	1.62 (1.30-1.94)	1.05 (0.90-1.20)	2.67 (2.27-3.08)
Self-pay/uninsured	211	1.74 (1.44-2.05)	0.33 (0.24 (0.42)	2.07 (1.76-2.38)

Schlenz et al, Needs Assessment of Sickle Cell Disease in South Carolina, Public Health Reports, in press

What age range do we need to target?



Is one area worse than others?



Are patients with sickle cell disease insured?

Rates of Acute Care Encounters per Patient by Age and Expected Payer

	Medicaid		Medicare		Private Insurance		Self-pay/Uninsured	
Age, y	n	No. (95% CI)	n	No. (95% CI)	n	No. (95% CI)	n	No. (95% CI)
0-9	386	2.49 (2.28-2.71)	3	1.00 (NA)	80	2.06 (1.76-2.36)	4	1.75 (NA)
10-17	185	2.58 (2.28-2.88)	4	2.25 (NA)	76	2.67 (1.85-3.49)	7	2.14 (NA)
18-30	315	8.05 (6.77-9.32)	154	12.17 (9.84-14.5)	136	3.48 (2.41-4.55)	108	2.10 (1.74-2.46)
31-45	131	6.76 (4.89-8.62)	181	8.03 (6.28-9.78)	101	2.63 (1.64-3.63)	65	1.91 (1.49-2.32)
46-64	40	5.05 (2.92-7.18)	135	3.53 (2.66-4.41)	88	2.14 (1.45-2.83)	27	2.37 (0.68-4.06)
≥65	0	NA	82	1.35 (1.18-1.53)	5	1.00 (NA)	0	NA

Abbreviation: CI, confidence interval; NA, not available

* Sample size too small to reliably calculate 95% CI, denoted by NA.

65% of individuals identified with sickle cell disease have Medicaid

25% of patients with SCD have Medicare

10% of patients have commercial insurance

10% of patients are not insured (some covered by DHEC)

Where are physician and Community stakeholders?

GHS: Pediatric Heme-Onc

LD Barksdale Sickle Cell Anemia Foundation

DHEC

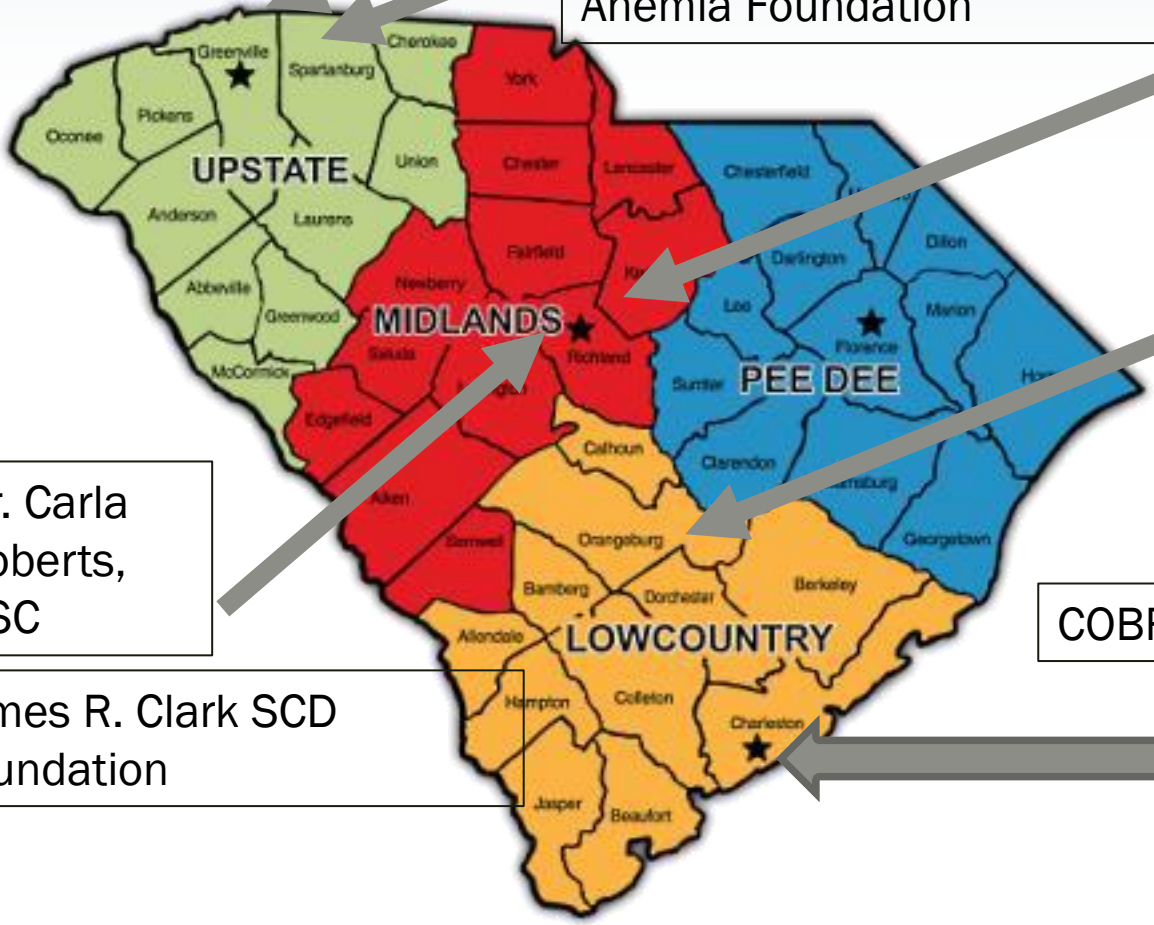
Orangeburg FOUNDATION

Dr. Carla Roberts, USC

COBRA FOUNDATION

James R. Clark SCD Foundation

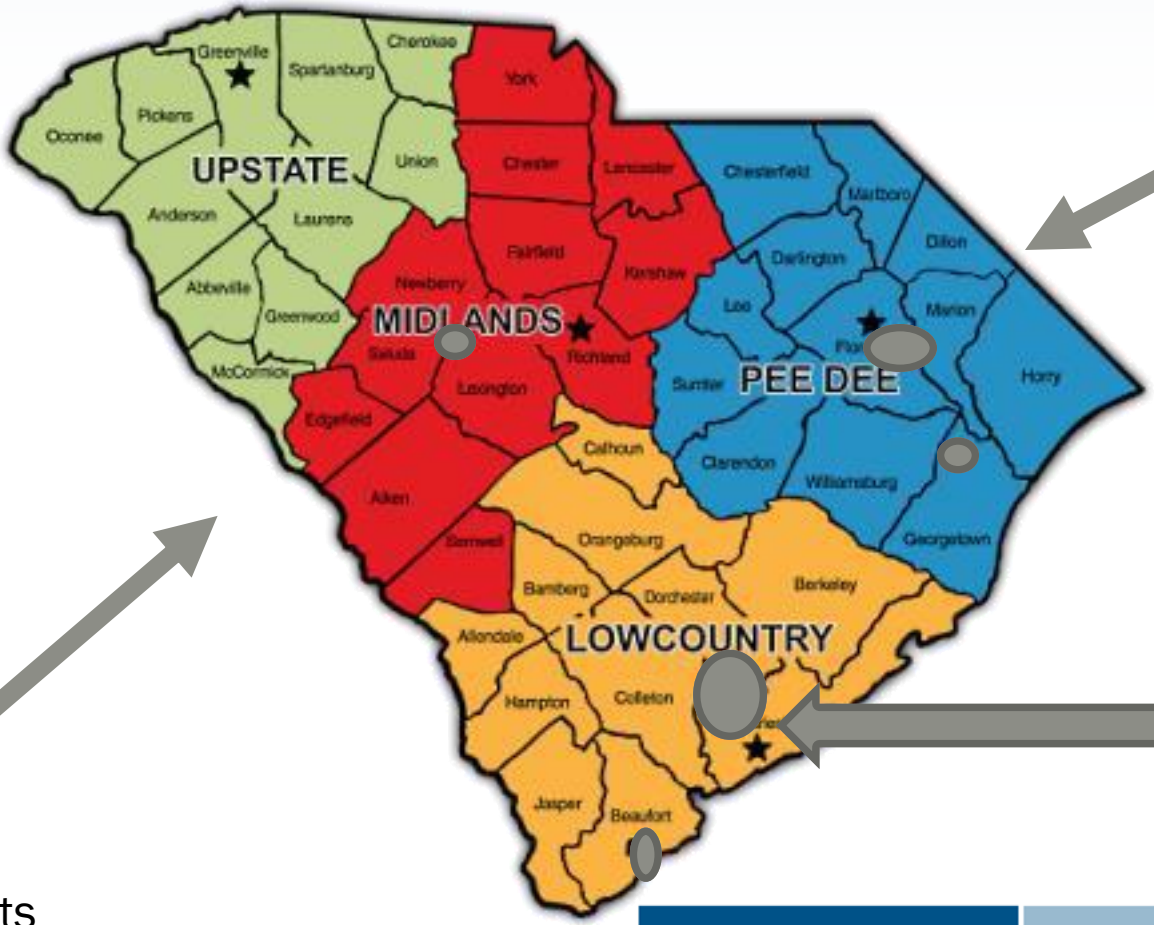
Sickle Cell Center



Where are the hospital stakeholders

300 patients

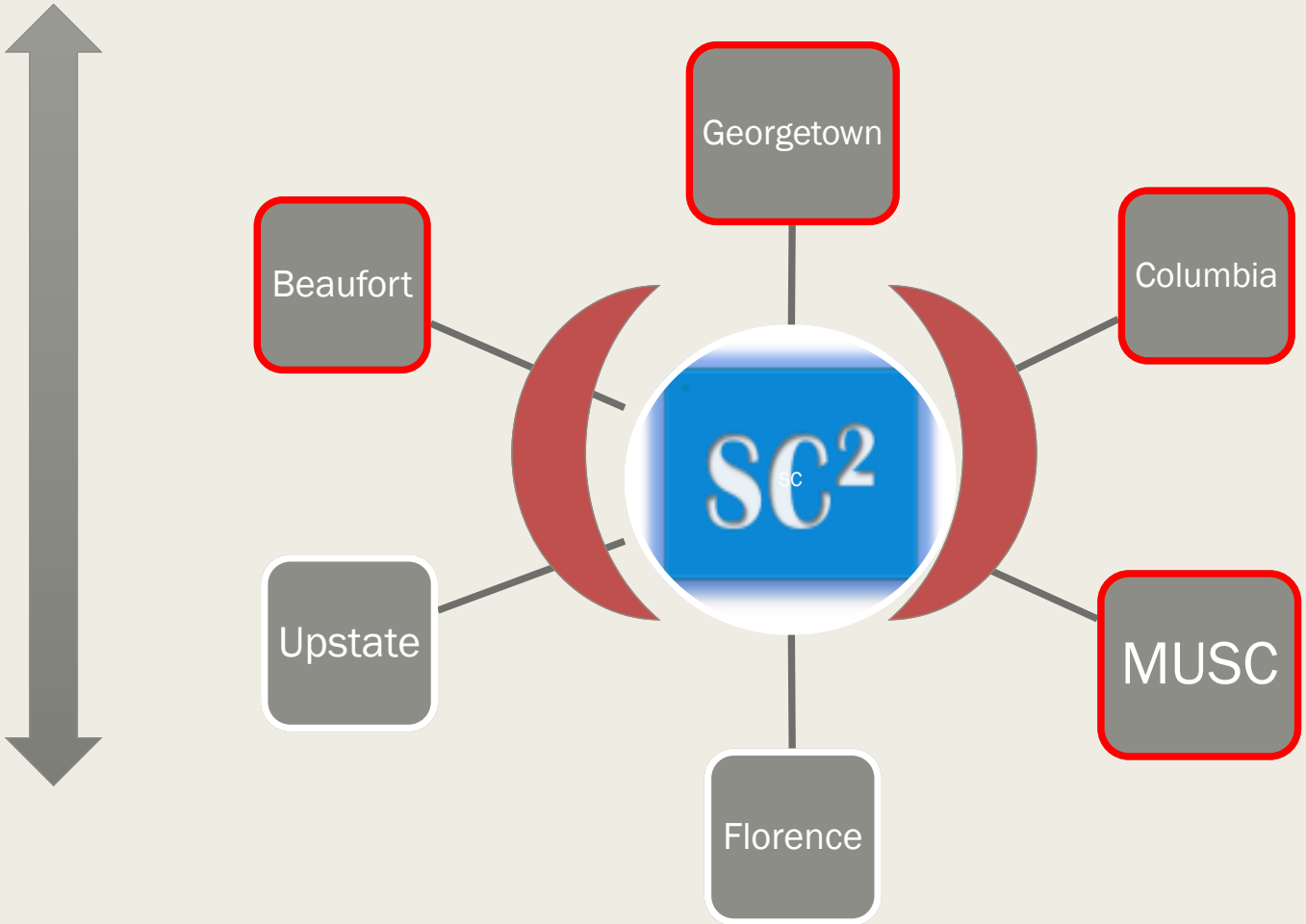
800 patients



2500 patients

1000 patients

Formulate a Plan:
Sickle Cell South Carolina SC^2



South Carolina Sickle Cell Disease Access to Care Pilot Program ($SC^{2)}$

- Hospital Based System (not a PCP based system)
- The SC^2 program is designed to increase access to care for all persons with SCD in South Carolina
- SC^2 includes both specialty and primary care
- Uses a hub-and-spokes care delivery model using a collective impact approach.
  - *In-person clinics*
  - *Telehealth clinics*
- This approach will both harness the resources of the state to approach SCD and will also use a technology-based approach to increase education of providers
  - *Telementoring (ECHO)*
  - *Annual Symposiums*

Methods:

People:

- SC^2 program coordinator to lead patient navigation, outreach clinic scheduling, coordinate meetings and educational symposiums
- SC^2 social worker to identify resources, provide social service support, insurance management, and address disease specific concerns.
- MD will Initiate weekly outreach clinics at identified sites to increase patient access to specialized SCD specific care and develop individualized education and treatment plans for affected patients

Information Technology

- Utilize an SC^2 SCD registry to enhance access to patient-specific individualized treatment plans for providers throughout the state
- Data assessment for quality improvement (*Care Coordination Institute)*
- Use telehealth for acute care needs at the individual medical homes
- ECHO program for educational conferences

Allies & Enemies

Allies and Enemies

ALLIES	ENEMIES
Hospitals	Hospital Physicians
Third Party Payers	Hospital Administrators
Hospital Administrators	Old “school” politics
Patients	Politicians
DHEC	DHHS

Overcoming Barriers

- Patience
- Staying Close to the Allies
- Staying away from the Naysayers
- Let someone else (BIGGER) introduce your ideas
- Bringing the Voice of Patients
- Build a team of supporters
- MONEY always talks

Common Goals and Quality Indicators

- CCI: Care Coordination Institute
- Measurable outcomes
  - *Improvement in Acute Care Utilization*
  - *Improvement in Hydroxyurea*
  - *Improvement in Preventative Care*
- Eye Exams
- Transfusion
  - *Patient Satisfaction*
  - *Provider Satisfaction*

SC^2 Sustainability

- Start Small and Grow
- Utilize the current payment structure to demonstrate that the SC^2 will generate sufficient revenue at individual spokes AND save on urgent care costs -- sufficient to support the continued efforts of the program
- Work with the centers for CMS and the state MCOs to develop a sustainable, reimbursable model for care in SCD
- Education of local providers
  - *The ECHO initiative has demonstrated that disease specific education can be accomplished through iterative practice, feedback, modeling, and mentoring through consultation*
  - *Teaching through consult (and sharing cell phone numbers)*
  - *Improvement in care of patients with SCD will also lead to the success and sustainability of the project*

Where are we now?

- **Very strong multidisciplinary Team**

- Cathy Melvin, PhD (Department of Public Health Sciences)
  - *Dissemination and Implementation Science Research*
- Julie Kanter, MD (Department of Pediatrics, Sickle Cell Center)
  - *Director of Sickle Cell Disease Research*
- Robert Adams, MD, MS
  - *Neurologist, Clinical Trial Expertise*
- Shannon Phillips, PhD, RN
  - *Expertise in Qualitative Research*
- Kit Simpson, PhD
  - *Health Outcomes Research Specialist and Cost Modeling*
- Alyssa Schlenz, PhD
- Psychologist, Developmental Pediatrics
- Martina Mueller, PhD
  - *Statistical expertise in qualitative assessments*

Where are we now?

- Sickle Cell State Committee 2015-2016
  - *Sickle Cell Disease State Committee: created and charged with better serving adults with sickle cell disease (SCD), and educating health care providers and the public about care and treatment.*
  - *The committee is to examine existing services and resources available to children with the disease as well as adults with the disease.*
- iSCENSC (Sickle Cell Disease Implementation Center)
- Multi-faceted awareness goals both locally and nationally
- Keeping up the motivation and momentum